

# Autism Advocacy in the Political Arena

by Ruth Snyder

Life is challenging for all of us. Yet some of us face greater challenges because of physical limitations that cannot always be seen and are often misunderstood. The feeling of being overwhelmed becomes normal for us, so we continue to cautiously live our lives, trying to avoid the proverbial final straw that would tip the scale against us. From what I have learned, politics in the United States of America is a taboo topic that can be overwhelming for anyone. But, in my opinion, choosing to remain uninvolved and uneducated leads to more serious problems.

For me, any natural desire to learn about politics was quickly stomped out when I was a child because my caregivers would not talk about political issues with me. Being exposed to only the tragic events in politics—as they were portrayed by the media—made the topic even less desirable to understand or learn. During one of the more challenging periods of my life, I found a wonderful group of self-advocates that were involved in politics. I was honored when they invited me to join them. That single event is what created my desire to become not only more of a self-advocate, but an *educated* advocate.

Regarding issues related to the autism spectrum, I quickly realized that much of our country was far behind in terms of information about, acceptance of, and respect for people affected by autism, which has led to a lack of appropriate services that could help individuals and families. Too many programs, it seemed, were chasing money instead of promoting truth, knowledge, and services. When I relocated to another area of the country, I was no longer able to connect with the self-advocates that originally mentored me. So I decided to look for more self-advocacy centers for people with disabilities. What I found shocked me.

For the first time in my life, I experienced what it felt like to receive condescending treatment. I was coddled like a puppy. This realization was a bittersweet one; I was hurt by the society's perception of me, but at the same time, I felt enlightened because I was finally able to recognize that people were patronizing me.

Someone I knew later explained to me that some organizations may have a “hidden agenda.” In fact, one disability organization revealed that the reason they did not want me to speak on their behalf (especially regarding political issues) was because I “would not support their agenda.” It took me a few months to figure out that they were correct. They were lobbying to obtain more funding for their organization and they were looking for a more needy representative of the autism community. As I began to meet some of the people being served in the organizations that obtained this funding; I decided that I could not support any organization that focused on (and consequently facilitated) people's disabilities, or supported keeping disabled people in institutions.

When the Combating Autism Act was passed in December 2006, several of us stepped up, without any support, to create a new self-advocacy movement motivated by self-preservation for others like ourselves. Our first lobbying efforts as a team took place on April 19, 2007.

The definition of the term “self-advocacy” is seemingly self-explanatory: a person with a disability advocating for what they want or need. Yet I have met many caregivers of individuals with disabilities (and organizations that support these caregivers) who tell the person what to do, what to say or not say, when to be at which event, and even sometimes cause them to behave at their worst instead of their best.

Unfortunately for all of us tax-paying self-advocates, our political leaders were not hearing our voices because many of us were not being taught how, when, or why to speak up. We were just taught what to do and say, if anything. In addition, when we, as disabled people, were not involved in the direct conversations with the political leaders, some of our non-disabled advocates were telling the leaders that disabled people could not speak for themselves.

A large majority of people with autism, myself included, have had their voices stolen, their words mistaken, or their opinions and needs dismissed because they could not communicate or behave in a way that was easily understood by the general public. The individuals that make up the masses are often too busy to hear our whispers, our songs, our screams, or our feelings. When we get politically active and we vote, we are making a difference, and our vote is equally counted with all the others. When we do not vote, we are letting others take our voices away, and sadly, our rights go away as well.

Self-advocates like me are out there fighting for our opportunity to make that choice for ourselves.